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# Patient Decision Making in Vestibular Schwannoma: A Survey of the Acoustic Neuroma Association

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## Abstract

**Objective.** To assess the decision-making process of patients with vestibular schwannoma (VS).

**Study Design.** Patients with VS completed a voluntary survey over a 3-month period.

**Setting.** Surveys were distributed online through email, Facebook, and member website.

**Subjects and Methods.** All patients had a diagnosis of VS and were members of the Acoustic Neuroma Association (ANA). A total of 789 patients completed the online survey.

**Results.** Of the 789 participants, 474 (60%) cited physician recommendation as a significant influential factor in deciding treatment. In our sample, 629 (80%) saw multiple VS specialists and 410 (52%) sought second opinions within the same specialty. Of those who received multiple consults, 242 (59%) of patients reported receiving different opinions regarding treatment. Those undergoing observation spent significantly less time with the physician (41 minutes) compared to surgery (68 minutes) and radiation (60 minutes) patients ( $P < .001$ ). A total of 32 (4%) patients stated the physician alone made the decision for treatment, and 29 (4%) felt they did not understand all possible treatment options before final decision was made. Of the 414 patients who underwent surgery, 66 (16%) felt they were pressured by the surgeon to choose surgical treatment.

**Conclusion.** Deciding on a proper VS treatment for patients can be complicated and dependent on numerous clinical and individual factors. It is clear that many patients find it important to seek second opinions from other specialties. Moreover, second opinions within the same specialty are common, and the number of neurotologists consulted correlated with higher decision satisfaction.

## Keywords

vestibular schwannoma, acoustic neuroma, decision making, shared decision making, patient satisfaction

Vestibular schwannoma (VS) is an uncommon benign tumor with an annual incidence of 1.1 to 1.2 per 100,000 people and a mean age at presentation of 46 to 55 years.<sup>1–6</sup> Recently, its diagnostic incidence has been on the rise, the suspected consequence of increased frequency of routine imaging among patients with headache or otologic symptoms. Treatment for VS can be broadly categorized into 3 groups: observation, stereotactic radiation, and microsurgery. Besides the presenting symptoms and its impact on quality of life, the decision-making process among these VS treatment options is oftentimes complex and multifaceted. These decisions can be influenced by numerous clinical factors, including but not limited to associated symptoms, tumor size, growth rate, patient age, and general health or comorbidities.<sup>1,2,7–12</sup> Online resources provided by organizations such as the Acoustic Neuroma Association (ANA) and other VS support groups aim to assist patients in better understanding all available treatment options and approaches.<sup>13–15</sup> In addition, second opinions from different specialists at various treatment locations coupled with insurance status may result in favoring one treatment option over another.<sup>16–19</sup> Other factors that may affect decision making include the variation of beliefs and opinions among physicians and family members, as well as patient coping mechanisms and expectations.<sup>11,13,20,21</sup>

As a result, numerous factors motivate a patient's treatment decision given that each treatment presents with its

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**Table 1.** Vestibular Schwannoma Treatment Modalities and Respective Mean Age and Tumor Size at Diagnosis.

Treatment	Participants, No. (%)	Age, Mean (SD), y	Tumor Size, Mean (SD), cm
Surgery	414 (52.5)	48.6 (11.3)	2.38 (1.33)
Radiation	224 (28.4)	55.6 (11.1)	1.72 (1.10)
Observation	121 (15.3)	57.2 (10.2)	1.12 (0.88)
Surgery + radiation	14 (1.8)	42.4 (13.0)	2.98 (1.31)
Undecided	16 (2.0)	56.9 (7.5)	1.70 (1.18)
Total	789 (100)	52.0 (11.8)	2.02 (1.28)

own unique set of considerations. We aimed to evaluate the various factors that play a role in the decision-making process from the patients' perspective. The utility of the study is to ultimately provide physicians with insight into subjective patient opinions on the decision-making process to optimize patient counseling and treatment experience.

## Methods

With institutional review board approval from the University of California, Irvine and in collaboration with the ANA, a voluntary and anonymous survey (Appendix 1, available in the online version of the article) was made available over a 3-month period spanning January to March 2017. Survey links were posted on the ANA website, Facebook page, and emailed to all members. Only patients diagnosed with VS were asked to participate. A total of 789 participants completed the questionnaire. The survey assessed self-reported patient demographics, tumor characteristics, physician appointments, information received, time delays, factors influencing the decision, and overall satisfaction with the decision. Patients in the surgery group (SG) underwent either complete or partial resection. Patients in the radiation group (RG) received radiation therapy or stereotactic radiosurgery. Patients in the observation group (OG) underwent serial magnetic resonance imaging (MRI) scans without radiation or surgery. The survey was administered via RedCap (Nashville, Tennessee). Statistical analysis was performed using PASW Statistics 18.0 software (SPSS, Inc, an IBM Company, Chicago, Illinois) with a  $P$  value of less than .05 considered statistically significant.

## Results

### Demographics, Treatment Modalities, and Tumor Characteristics

Of the 797 questionnaires that were received, 789 were analyzed as complete surveys. The study sample was composed of 65.4% females with key characteristics and treatment modalities outlined in **Table 1**. The average interval between time of diagnosis and survey participation was 7.18 years (range, 1 month to 45 years).

### Important Decision-Making Factors

When asked about the most influential factor in deciding treatment, physician recommendation (62.0%) was most

common, followed by quality-of-life concerns (54.5%), tumor size (49.5%), symptoms at the time of diagnosis (27.1%), complication risk (20.5%), dissatisfaction with other treatment options (19.2%), information on the ANA website (17.4%), and Internet research (12.7%).

When considering the number of neurologists, neurosurgeons, and radiation oncologists visited, 629 (79.7 %) of the patients visited more than 1 specialist (mean, 3.1 specialists) (**Table 2**). A total of 410 (52.0%) sought second opinions within the same specialty (eg, visited 2 or more different neurologists). When seeking a second opinion, 40.7%, 24.3%, and 7.9% of the patients visited more than 1 neurosurgeon, neurotologist, and radiation oncologist, respectively (Supplemental Table S1, available in the online version of the article). Among those with multiple consultations, 242 (38.5%) received different opinions regarding treatment management. The primary determining factor for decision making between discordant opinions was personal choice in 139 (57.4%), concerns for treatment complications in 127 (52.5%), online research in 124 (51.2%), ANA information or ANA member suggestions in 89 (36.8%), and concerns with success rate in 62 (25.6%) of patients.

### Decision Making: Time Delay between Diagnosis and Decision

Only 5% of the survey responders made a decision of treatment at the time of diagnosis. The average time from diagnosis to treatment decision was 97.6 days (median, 30 days). On average, the SG took 63 days, RG 169.2 days, and OG 75 days before making their treatment decision. Of note, the initial diagnosed tumor size negatively correlated (Pearson correlation =  $-0.177$ ) with time taken to decide on surgery ( $P = .001$ ). The most frequent reason for time delay between diagnosis and treatment was seeking a second opinion in 306 (38%), scheduling in 176 (21.8%), and observation until deciding active treatment in 124 (15.6%) of the patients.

### Time Spent Discussing Treatment Options

The survey participants spent an average of 60.9 minutes discussing management options with their primary VS-treating physician (range, 2 minutes to 6 hours). The SG spent 68.4 minutes (range, 2 minutes to 5 hours), RG 60.1 (range, 10 minutes to 6 hours), and OG 41.3 (range, 5 minutes to 4 hours). This time included multiple visits with these specialists. The OG spent less time with their treating physician compared

**Table 2.** Percentage of Each Treatment Group Visiting at Least 1 Neurosurgeon, Neurotologist, and Radiation Oncologist.

Treatment Group	Seen at Least 1, %		
	Neurosurgeon	Neurotologist	Radiation Oncologist
Surgery	90.3	81.9	24.4
Radiation	90.5	53.6	75.4
Observation	66.9	63.7	30.6
Total	85.9	69.4	40.6

other groups ( $P < .001$ ). Neurotologists, neurosurgeons, and radiation oncologists spent an average of 63.7, 60.4, and 59.9 minutes with their patients, respectively.

### Shared Decision Making and Change in Decision

In total, 55.5% (434) of the survey responders stated they made the treatment decision on their own, 39.6% (316) made it together with their physician, and 4% (32) stated that the physician alone made the treatment decision. Of the 32 participants who stated the physician alone made the decision, 21 (66%) underwent surgery and 11 (34%) underwent radiation. Of the patients who made the decision alone compared to those who made it with their physician, the latter had a significantly larger tumor size at diagnosis (mean, 1.80 cm vs 2.12 cm;  $P = .001$ ) and took a significantly shorter amount of time to make the decision (mean, 278.5 days alone vs 74.7 days with physician;  $P = .004$ ).

Of the 417 patients with VS who underwent surgery, 66 (15.6%) specifically felt the surgeon pushed the surgery option on them. Moreover, 29 (3.8%) of the survey responders did not feel informed or fully understand all possible treatment options. In turn, 78.2% (594) of patients felt very informed and understood all possible treatment options, while 137 (18%) felt moderately informed. Last, 10.1% (79) of the sample changed their final treatment decision after an initial treatment decision was already made.

### Satisfaction with Decision

In our sample, satisfaction with the ultimate treatment decision did not differ between the SG and RG ( $P = .119$ ), SG and OG ( $P = .773$ ), and RG and OG ( $P = .184$ ). Also, there was no difference between active treatment (SG or RG) and observation (OG;  $P = .471$ ) with regard to satisfaction with the ultimate treatment decision (**Table 3**). Bivariant Pearson correlation was conducted to assess correlations between decision satisfaction and tumor size, age at diagnosis, days taken to decide, minutes spent with the primary VS treating physician, and number of specialists seen. Only the number of neurotologists visited resulted in a statistical increase in satisfaction ( $P = .005$ ;  $r^2 = 0.011$ ).

### Discussion

We have demonstrated that the decision making of patients with VS with regard to ultimate treatment is influenced by a

number of factors. This study evaluates the decision-making process from the patients' perspective, providing valuable insight into the variables important in influencing patient decisions and posttreatment satisfaction. The sample's average age, tumor size, and treatment distribution are consistent with data presented in the literature of large cohorts of patients with VS, supporting the study validity.<sup>2,4,13,22</sup>

### Physician Recommendation and Informed Consent

The data revealed that 60% of patients list physician recommendation as one of the top 3 most influential factors when determining ultimate treatment options. Similarly, a study of British patients with VS reported that their decision making was influenced by their physicians in 80% of the participants.<sup>13,23</sup> It has been previously demonstrated that 41% of a sample of 739 surveyed patients had unanswered questions due to inadequate time with the physician.<sup>24</sup> Others have reported that 32% to 69% of patients were not informed of other treatment options, with 14% to 29% feeling pressured for a specific treatment.<sup>13,25</sup> These data are consistent with our findings that 16% of the SG felt the treatment had been pushed upon them, 4% of all patients felt powerless in decision making, and 3.8% of the survey responders were not informed about all the treatment options. Although this occurred to a relative minority of patients, its occurrence is noteworthy, given the importance of physician recommendation. Interestingly, the average patient spent 62 minutes with his or her treating physician, with the increased time not resulting in higher patient satisfaction.

### Secondary Consultation

It is not uncommon for patients to seek multiple consultations. A systematic review of oncology patients demonstrated that 6.5% to 36% of patients sought second opinions.<sup>26</sup> Although VS is unique due to the variety of comparable treatment options, our study revealed that 80% of patients visited more than 1 VS-treating specialist (defined as a neurotologist, neurosurgeon, or radiation oncologist). Our sample visited an average of 3 specialists overall, but at least 2 neurosurgeons, neurotologists, and radiation oncologists were seen by 40.4%, 24.3%, and 7.9% of patients, respectively. It is thought that consulting multiple treating experts can either validate previously discussed options or present discrepancy in opinions. Tattersall and colleagues<sup>16</sup> found in their institutional study among general oncology patients that secondary consultation resulted in 50% of patients receiving new information and 40% of patients changing their treatment decision. Mellink et al<sup>27</sup> found that 68% of oncology patients seeking a second opinion obtained validation of previous recommendations, while 32% faced various levels of discrepancy. This is consistent with our sample, in which 30% of patients received different opinions from specialties for treatment recommendations. In light of this, physicians may help facilitate treatment decisions by offering second opinions through an open discussion with colleagues and specialists both within and outside their own field to help ensure proper and informed decision making on the patients' behalf.

**Table 3.** Patients Satisfaction Based on the Treatment.

Treatment	Extremely Dissatisfied, No. (%)	Very Dissatisfied, No. (%)	Satisfied, No. (%)	Very Satisfied, No. (%)	Extremely Satisfied, No. (%)	Mean (SD)
Surgery (n = 406)	10 (2.5)	25 (6.2)	117 (28.7)	108 (26.6)	146 (36.0)	3.87 (1.05)
Radiation (n = 215)	11 (5.1)	14 (6.5)	53 (24.7)	54 (25.1)	83 (38.6)	3.86 (1.16)
Observation (n = 103)	2 (1.9)	7 (6.8)	36 (35.0)	29 (28.2)	29 (28.2)	3.74 (1.01)
Total (N = 724)	23 (3.2)	46 (6.4)	206 (28.5)	191 (26.4)	249 (34.4)	3.83 (1.09)

### Role of Outside Resources

When facing discrepancies in recommendations by the treating physician, 51% of patients sought information online, with 37% benefiting from ANA's information and virtual relationships with members specifically. As a result, 29% of the sample reported that ANA information or general Internet research played a significant role in decision making. The utility of the ANA and other informational and support groups has been previously well described, proving to be beneficial in providing useful information that is communicated from patient to patient.<sup>15,21</sup> Despite the critical role these resources often play, a physician's endorsement of these communities that provide valuable information at the expense of potential dissemination of misinformation is largely unknown at this time.

### Patient Satisfaction

Overall, 85% of the studied sample stated that they were satisfied with their decision. This is despite evidence that patients with VS have a lower quality-of-life (QoL) score compared to patients with head and neck cancer.<sup>10,21</sup> In addition, no difference in decision satisfaction between SG, RG, and OG was observed. This is in line with literature demonstrating no change in QoL between the 3 treatment groups.<sup>28-32</sup> Interestingly, time taken to decide on treatment or amount of time spent discussing treatment options with the treating physician did not affect decision satisfaction. Our results indicate that the number of different neurotologists visited, but not neurosurgeons or radiation oncologists, correlates with a higher decision satisfaction of the survey responders. However, the  $r^2$  of .011 suggests that a very small portion of the variation in satisfaction is explained by the number of neurotologists seen.

### Limitations

As with any retrospective self-reporting study, the possibility of recall bias as well as participation bias could play a substantial role in skewing data. Of significance, targeting ANA members may represent a small and biased sample of the VS population that are comfortable with technology and are able to identify and obtain online support and resources when making treatment decisions. In addition, expecting patients to recall information and feelings regarding events that took place from years prior may introduce a variety of inconsistencies and issues. We attempted to overcome these limitations

by increasing the sample size of our study, yet these limitations may be addressed with future prospective randomized survey-based studies enrolling a less biased cohort.

### Conclusion

With the continuing evolution and refinement of treatment modalities, patient decision making in VS is influenced by numerous factors. These include physician recommendation and the amount of time spent discussing treatment, number and types of specialists visited, and online resources. Considering that a small proportion of patients with VS feel pressured into choosing a specific treatment or do not feel informed about all possible options, seeking second opinions and impartial discussion with the patients may help better inform these patients and improve ultimate satisfaction.

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### Author Contributions

**Omid Moshtaghi**, study concept and design; drafting/revising the manuscript for content, analysis, and interpretation of data; accepts responsibility for conduct of research and final approval; **Khodayar Goshtasbi**, study concept and design, drafting/revising the manuscript for content, analysis and interpretation of data, accepts responsibility for conduct of research and final approval; **Ronald Sahyouni**, study concept and design, drafting/revising the manuscript for content, analysis and interpretation of data, accepts responsibility for conduct of research and final approval; **Harrison W. Lin**, study concept and design, drafting/revising the manuscript for content, analysis and interpretation of data, accepts responsibility for conduct of research and final approval; **Hamid R. Djalilian**, study concept and design; drafting/revising the manuscript for content, analysis, and interpretation of data; accepts responsibility for conduct of research and final approval.

### Disclosures

**Competing interests:** Hamid R. Djalilian, has equity in Beyondtinnitus.com.

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## Supplemental Material

Additional supporting information is available in the online version of the article.

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